

Health Care Law

Mid-Atlantic Ethics Committee Newsletter

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Mid-Atlantic Ethics Committee
Newsletter, Fall 2008

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MID-ATLANTIC ETHICS COMMITTEE

NEWSLETTER

A Newsletter for Ethics Committee Members in Maryland, The District of Columbia and Virginia
Published by the Law & Health Care Program, University of Maryland School of Law
and the Maryland Health Care Ethics Committee Network

Fall 2008

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The Mid-Atlantic Ethics Committee Newsletter is a publication of the Maryland Health Care Ethics Committee Network, an initiative of the University of Maryland School of Law's Law & Health Care Program. The Newsletter combines educational articles with timely information about bioethics activities. Each issue includes a feature article, a Calendar of upcoming events, and a case presentation and commentary by local experts in bioethics, law, medicine, nursing, or related disciplines.

Diane E. Hoffmann, JD, MS
Editor

WHEN RESPECTING PATIENTS' WISHES PUTS THEM IN HARM'S WAY

An ethical *dilemma* involves having to make a choice between alternatives that require compromising one or more ethical principles. Consider the situation of a debilitated yet competent adult patient who insists on returning to a home environment that health care professionals (HCPs) think is unsafe. Imagine that the patient cannot take care of her basic needs (for example, cooking, bathing, answering the door, housecleaning), and that she has run out of money to pay for the help she would need to maintain a safe home environment for herself. She might qualify for Medicaid to pay for a nursing home stay, but not for the home care needed to keep her well cared for in her home. The patient is adamant that she would rather die in her own home than go anywhere else—particularly a nursing home.

In such a situation, two fundamental ethical obligations appear to be in direct conflict: (1) the duty to promote the patient's well-being and protect the patient from harm and (2) the duty to respect the wishes of a competent patient. HCPs who become involved in caring for such a patient would be justifiably concerned that the patient's well-being is threatened and that the potential for harm is great if she returns to her home under these circumstances. At the same time, HCPs may be troubled by the prospect of overriding the patient's wishes.

The AMA Principles of Medical Ethics state that "[a] physician shall respect the rights of patients." Among other rights,

patients are acknowledged to have the right of self-determination. Of course, this hasn't always been the case in American medicine. As recently as the 1950's and early 1960's, HCP's were often quite paternalistic towards patients. In the context of complex shifts in social norms in the 1960s and 1970s, patient autonomy became established as a dominant principle in bioethics. As a result, the patient's status in the patient-HCP relationship has evolved to include patient involvement in medical decision making. But, does the right of patients to decide for themselves extend to the right to make a bad decision?

Patients have the right to define for themselves the values and goals that will determine their medical care. These values and goals inform decision making about specific medical interventions; e.g., deciding between alternative treatment approaches. To facilitate this right of patients to be self-determined, physicians should adopt a patient-centered approach, taking care to determine the patient's values and goals of care, as well as eliciting the patient's perspective on their illness. It is often difficult for physicians and other members of the health care team to accept patients' decisions that depart from a professional's recommended course of action, which is intended, of course, to benefit the patient. Even though such decisions may preclude benefit in a biomedical sense, decisions that are congruent with patients' values and goals may benefit patients in other ways. Patient choices that endanger their

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***When Respecting Patient's Wishes Puts
Them In Harm's Way
Cont. from page 1***

well-being and appear to conflict with their own stated values and goals are especially difficult to accept because they appear to be not only "bad" from the medical perspective but also irrational. It is important for physicians to identify the underlying cause for irrational decision making and approach it appropriately (Brock & Wartman, 1990).

Many authors have expressed concern that one consequence of overly strict adherence to the principle of patient autonomy is that other important principles (such as the duties to benefit and protect patients) receive insufficient priority. This imbalance might result in an inappropriately limited role for patients' physicians in important medical decisions. The goal, it is argued, should be to strike a proper balance between autonomy and beneficence that would include a healthy respect for patient self-determination without abandonment of the duty to benefit patients (Pellegrino & Thomasma, 1988). This approach would allow physicians a meaningful role in the patient-physician relationship and in medical decision making, one that includes looking out for the well-being of their patients while avoiding backsliding toward paternalism. In general, however, patient decisions are honored. This is true even if patient decisions are perceived by their physicians to be "bad" or "irrational," unless there is a threat of harm to a third party, an inadequately treated psychiatric illness, or a concern about capacity. Although concerns about patient capacity should not be limited to occasions when physicians consider patient choices to be "bad" or "irrational," it certainly makes sense that such choices would raise these concerns.

Methods of assessing decisional capacity typically identify several essential functional abilities and, in this way, differ from measures of mental status, such as the Mini-Mental State Examination. These abilities include making and communicating a choice; understanding relevant information about the medical situation; appreciating that the relevant

information applies to oneself in the situation at hand and, perhaps, in the future; and engaging in rational deliberation about treatment options and being able to describe why one particular choice was made, rather than another, based on one's own values (Grisso & Applebaum, 1998). A bedside tool to evaluate capacity for treatment decisions is available and it has been empirically studied, yet time considerations may limit its widespread application in clinical practice (Grisso, Applebaum, & Hill-Fotouhi, 1997).

Some authors have argued for a flexible standard with respect to decisional capacity: the idea that as the risk of harm increases, the criteria for capacity should accordingly become more stringent (Buchanan & Brock, 1989). For example, it may not be sufficient that the patient has consistently expressed a strong desire to remain in her home. The patient should also demonstrate that she appreciates the potential harms she may encounter if she remains in her home. Also, while a patient's consistently stated preferences should be given proper consideration, the HCP should keep in mind that patient preferences may appropriately change over time or as circumstances change, and reassess accordingly.

There are many possible responses to a patient who refuses treatment recommendations. In particularly frustrating cases, some HCP's are tempted to disengage and accept patients' decisions out of resignation or even anger. Although this approach may seem easier for the physician, it may not serve patients' best interests. Alternatively, physicians may reject a patient's refusal and attempt to impose treatment (e.g., transfer to a rehab facility) through whatever means available, including pursuit of legal options through the courts. In many states, in the absence of a mental illness associated with dangerousness to self or others, attempts to force placement or treatment against a patient's will can only be pursued if the patient is deemed by a judge to be incompetent. Another response to treatment refusal is to explain the physician's perspective to

the patient, attempting to persuade the patient to change his or her mind while avoiding manipulation or coercion.

When a patient refuses the recommended plan of care, physicians should regard such resistance as an opportunity to initiate (or continue) dialogue in an effort to understand the patient's perspective. What factors are contributing to the patient's point of view and influencing her decision making? Have members of the health care team considered and explored religious beliefs, cultural background, various psychosocial factors, previous interactions with the health care system, influential personal experiences, or the preferences of family members or friends? The physician should determine the consistency of the patient's choice vis-à-vis the patient's values and goals. Is the proposed choice compatible with the achievement of those expressed goals? Is it the best choice to achieve those goals? For example, would the patient consider short-term treatment in a rehab facility to maximize her health and functional ability in order to achieve her ultimate goal of remaining in her home long-

term? Have all options been explored to provide home care assistance? Careful consideration of these issues could lead to better ways of communicating with the patient and, ideally, to better decisions and outcomes.

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REGIONAL NEWS

The Maryland Health Care Ethics Committee Network co-sponsored a series of "journal club meetings" in October to show and discuss the documentary, "Health, Money & Fear." The 50 minute documentary summarizes what is wrong with our health care system, and what we need to do to fix it.

On December 3, 2008, MHECN co-sponsored the conference, "Health Care Ethics Committees and Maryland Law – Time for a Change?" at Broadmead in Cockeysville, MD. See p. 11 (Box) for more information about this conference.

In the summer of 2009, MHECN will present its biennial basic ethics educa-

tion conference for ethics committee members. Information about this conference will be available in the Spring of 2009. Contact info: MHECN@law.umaryland.edu, (410) 706-4457..

The Montgomery County Coalition for End of Life Care has recently created a simplified advance directive form that focuses on appointing a health care agent and identifying preferences for end of life care to inform the health care agent. The Coalition hopes that this form will be simpler to understand than the current Maryland living will form, and that it will support more effective end-of-life decision-making than a traditional living will. To request a copy of the form, e-mail Dr. Barbara Blaylock at b.blaylock@verizon.net.

The State Advisory Council on Quality Care at the End-of-Life met on October 10, 2008. The Council discussed a memorandum generated to compare Maryland's Life-Sustaining Treatment Options ("LST") form (formerly the "Patient's Plan of Care Form") to the Physician Orders for Life-Sustaining Treatment ("POLST") form. The POLST is a physician's order while the LST form is a document expressing the patient's current treatment preferences with the hope that physicians' orders will be generated that are consistent with those treatment preferences. For more information about the Council's meetings and activities, visit <http://www.oag.state.md.us/healthpol/SAC/index.htm>.

HEALTH CARE REFORM: UNINTENDED CONSEQUENCES OF REGULATION

The last issue of the MAEC Newsletter featured a summary of talks given at a conference that MHECN sponsored on April 7, 2008, entitled "The Ethics of Health Care Reform." A central theme that ran through many of the talks was that of improving the "cost-effectiveness" of our health care system. Here, Rebecca Elon provides a note of caution regarding unintended consequences of health care reform efforts intended to control costs.

"It is your duty to devote yourselves to your patients and your practice. If you are diligent in your work, society will reward you amply. You should be interested in medicine, not money. If it is money that interests you, go work on Wall Street."

With that rebuke, my 80 year-old elder colleague left the room. I was left behind with 15 second-year medical students who had been discussing the various salaries they could expect to earn in different medical specialties after graduation. My colleague had been a private attending physician at the academic teaching hospital since the mid 1950's. He practiced during an era when medicine was a sovereign profession with more moral authority than economic power. Today, however, the opposite seems true. Medical students cannot understand the vast health care industry they are entering without reading the Wall Street Journal in addition to the New England Journal. Many medical students are leaving their training with \$150,000 or more in educational debts, and finding that primary care fields and jobs with underserved populations may not allow them to service their academic debts

and live the lifestyle they believe they should be entitled to enjoy. Instead of entering fields in which they are interested or which they believe to be good for society, many graduates are entering fields that will minimize their hours worked per week and maximize their earning potential.

In the absence of a healthy social covenant, can we blame them? We as physicians have become a constantly hurried and harried group of "piece workers." Since we are paid by the visit or the procedure, as the payment per "piece" falls, the only way to maintain income in the face of rising costs is to increase the volume of services provided. Patients have become our means of production. Since each "piece" of work has become devalued, physicians must perform higher volumes to meet their budgets. For example, if a primary care physician does not make 24 to 30 billable visits per day, he may not be able to meet his overhead expenses. The non-reimbursed aspects of care, such as case management and communication, fall by the wayside. Since medicine has become commodified, there is less emphasis on doctor patient relationships, and more emphasis on the elements within the

interaction that serve to justify the reimbursement. Both physicians and patients are feeling discontent within the current status quo. Both groups blame "the system." How did we get here? Why is our health care system too expensive, uncoordinated, lacking in prevention, with inadequate continuity of care and care coordination? Why are those who deliver care, those who receive care, and those who pay for care all dissatisfied? If we look back historically, we find that it is past reform efforts that have led us to where we are today. Consider the examples listed below (see Box) of some unintended consequences of laws or regulations affecting health care delivery in the U.S..

Current efforts at health care reform often punish good people working within bad systems. American physicians and health care workers today often feel under siege and victimized by reform efforts foisted upon them. The dominant "-ism" of modern secular American life may in fact be "regulatorianism," in that we seem to believe that most of the ills of our society can be corrected or reformed through the promulgation of more and more governmental regulations. Regulations are now expected

Law/regulation	Unintended Consequence
Social Security Act (1935)	Encouraged the expansion of the private pay, for-profit LTC industry.
Hill Burton Act (1946)	Encouraged expansion of institutional capacity in the care for frail elders and disabled persons.
Medicaid legislation (1965)	Shifted financial responsibility from family to state for care of elders; became a form of universal institutional LTC insurance.
Medicare legislation (1965)	Medical inflation 1970's to present followed by cost control efforts 1980's to present (e.g., DRG/PPS, physician fee setting); earlier hospital discharge; growth of sub-acute care nursing home beds created cost shifting to LTC; physicians limiting or opting out of Medicare.

DRG – diagnostic related groupings (a form of prospective payment)
PPS – payment for performance
LTC – long-term care

to tell us how to do the right thing the right way. In former times, it was our religious upbringing and/or educational training that taught us how to do the right thing the right way. As physicians, our professionalism guided our actions and formed the governance structures in medicine. In American health care reform, however, the dominant 20th and 21st century ethos of professionalism is increasingly yielding to federal regulationism.

A couple of years ago I received a notice from Medicare that I had tripped the “99214 wire.” The warning letter claimed that I was an outlier relative to my peers, billing too high a percentage of my outpatient visits at the higher level code. The letter warned that I should be absolutely sure that my documentation justified such billing since tripping the wire placed me at risk of audit. Of course, I was an outlier relative to my internal medicine peers! I am a geriatrician. I cared for more people over the age of 90 than below the age of 60. We scheduled 30 minute follow up visits for this population.

Although I felt we were in compliance with our billing practices, this letter caused me to experience significant anxiety every time I sat down to write a chart note. We were still using 19th century paper charts. I wanted to document more than usual, which took me more time. Still, I could not be sure that I had documented all the requirements each time to bill at what was the appropriate level based upon the time involved. I felt compelled to under code the visit, and bring myself into alignment with my internal medicine peer group, for fear of having an audit conducted on my work. I knew people who had undergone audits, and it was an absolutely awful process, even if in the end they were vindicated. My down coding resulted in increasing financial pressure on me from the hospital that owned our practice. The budget had become an unsolvable problem for me in a fee for service Medicare environment. I could not provide high quality care and meet budget.

I quit the practice at the age of 53, to try to find a different way of providing

quality care for frail elders in community settings.* I convened a symposium for all the hospital sponsored geriatric medicine programs in the Baltimore Washington area about how to drop out of Medicare. I was making plans to do so

The current call for accountability in medicine cannot be met by payment schemes such as pay for performance. Pay for performance schemes are reductionistic, and do not capture overall quality of care.

myself. Medicare, it seemed to me, had become one of the biggest obstacles for providing quality care to frail elders.

The current call for accountability in medicine cannot be met by payment schemes such as pay for performance. Pay for performance schemes are reductionist, and do not capture overall quality of care. For example, if an insurance company plans to pay more to a physician whose diabetic patients have Hemoglobin A 1 C (blood sugar) measurements below 7% rather than to the physician whose diabetic patients have an average Hemoglobin A 1 C of 8%, the insurance company may be inadvertently rewarding a physician whose patients are less challenging and more adherent to their medical plans of care. The physician may have “cherry picked” his patients, and turned away the more challenging patients who would threaten his ability to meet the benchmark. The physician with the worse performance measure may have worked skillfully and much harder with more difficult patients to have achieved the poorer number. The 8% may reflect an improvement for the difficult patients from 9% or 10% and actually represent a remarkable achievement. But if the benchmark is 7%, the physician will not be rewarded for his diligence and good work.

Med Chi, the Maryland Medical Society, recently held a series of symposia to teach primary care physicians in the state what is expected of them from pay for performance criteria from various insurers and national organizations measuring quality of care. The presentations were overwhelming to the attendees (myself included). Most small practices cannot

invest the time required to learn all of the differing requirements and do not have the infrastructure to collect and report the information being requested. Medicare was surprised that in the first year only 16% of physicians partici-

pated in the voluntary Product Quality Research Institute (PQRI) measures that could result in up to a 1.5% increase in payment. Most small practices do not have the capacity to capture and report the requested information.

The momentum in medicine is toward increasing industrialization and consolidation. Small practices will need to find ways to work collectively and collaboratively in the data collection functions. Whether the concept of ‘accountable care systems’ will be able to connect small practices and provide the needed infrastructure is uncertain. Small practices may be destroyed over time and be replaced by larger corporate owned practices that have the infrastructure to do the reporting that is currently being requested on a voluntary basis, but may well be mandatory in the near future.

As Derek Bok said in his book, *The Trouble with Government*, “Even the most perfectly crafted compensation scheme cannot ensure a perfect balance between cost and quality of care. Medical care requires innumerable judgments for which there is no one obvious answer.” Similarly, health care reform requires innumerable judgments for which there is no one obvious answer. As current discussants describe the American health care system as “a mess,” it is useful to remember how we arrived at the current messy situation. The answer lies in the efforts of reform movements of the past, with all of their intended and unintended consequences. Our current system of health care in America can perhaps be defined as the sum of the intended and unintended consequences of past legislative, judicial and regulatory

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PHILOSOPHER'S CORNER: WHAT DO WE MEAN BY *DIGNITY*?

In contemporary bioethics, few moral terms are more invoked and less defined than “human dignity.” The phrase first appeared in the English language in 1225, but its meaning is anything but settled. In the context of physician-assisted suicide, for example, human dignity has been used by parties on both sides of the issue to mean quite different and sometimes contradictory things. Opponents of physician-assisted suicide argue that the practice undermines the dignity (worth) of elderly and disabled patients, while defenders of physician-assisted suicide claim that the practice respects the dignity (autonomy) of patients. Competing uses of dignity also appear in discussions about stem cell research, human enhancement, and cloning.

The term *dignity* plays a central role in a number of recent bioethics documents as well, including the President’s Council on Bioethics report entitled *Human Cloning and Human Dignity* (2002), the Council of Europe’s *Convention for the Protection of Human Rights and Biomedicine* (1997), the World Health Organization’s *Ethical, Scientific and Social Implications of Cloning in Human Health* (1997), and UNESCO’s *Universal Declaration on the Human Genome and Human Rights* (1997). None of these documents, however, set forth a definition of dignity.

In their defense, one might argue that dignity is a simple concept that does not require definition. However, the very fact that people on opposite sides of a given issue can appropriate the term to advance their agenda suggests that our ordinary way of talking about dignity is confused and vague. If dignity is to exhibit any moral force in bioethics, it is important to understand its history and possible meanings.

The word dignity comes from the Latin root *dingus*, meaning worthy. Its earliest English meaning referred to a person’s rank. According to this pre-Enlightenment understanding of the word, kings, bishops, and noblemen had dignity; commoners did not. Dignity

was variable; it could be gained or lost, depending on a person’s status at any given time. Though this view of dignity largely vanished during the Enlightenment, it still persists today when one talks about honoring dignitaries based on their elevated status.

A second meaning of dignity can be traced to Aristotelian notions of virtue. Dignity of this kind applies to people who exhibit, through their actions, excellent character. Unlike dignity based in rank, this version of dignity has nothing to do with hierarchy. A slave stripped of the rights of citizenship could maintain dignity of this sort if he comported himself in a virtuous manner. People who possess this form of dignity often exhibit qualities like perseverance, composure, self-respect, decency, and fairness.

During the Enlightenment, an egalitarian notion of dignity surfaced that granted dignity to all humans regardless of rank or virtue. This type of dignity is concerned with the *equality* of lives, not the *quality* of lives (Meilaender, 2008). It starts from the premise that all humans have permanent and equal worth, either because they are made in the image of God (the theological account) or because of some quality of their humanness (the philosophical account).

A fourth meaning of dignity, which emphasizes autonomy and free choice, grew out of the Kantian idea that people have dignity by virtue of being rational selves capable of making and applying universal moral laws. In the West, this vision of dignity generally is invoked to protect individual choice and self-determination. This use of dignity is so pervasive in American bioethics that at least one critic has questioned whether dignity ever means anything other than autonomy (Macklin, 2003).

A fifth meaning of dignity, rooted in communitarianism, suggests that dignity can operate as something other than autonomy. This approach to dignity, which is more traditionally found in Europe than America, focuses on what kind of society best protects the dignity of

humanity on the whole. It places limits on individual choices in order to protect the excellence of humanity and avoid its degradation.

As these various meanings demonstrate, dignity is a multifaceted concept. It is far easier to invoke than to define or defend. The challenge is to articulate what we mean when we use the term. Anything less will jeopardize our ability to appeal to dignity in a normatively meaningful way.

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CASE PRESENTATION

One of the regular features of the Newsletter is the presentation of a case considered by an ethics committee and an analysis of the ethical issues involved. Readers are both encouraged to comment on the case or analysis and to submit other cases that their ethics committee has dealt with. In all cases, identifying information about patients and others in the case should only be provided with the permission of the patient. Unless otherwise indicated, our policy is not to identify the submitter or institution. Cases and comments should be sent to MHECN@law.umaryland.edu, or MHECN, the Law & Health Care Program, University of Maryland School of Law, 500 W. Baltimore St., Baltimore, MD 21201.

CASE STUDY FROM A MARYLAND HOSPITAL

Mr. P. and his daughter are hoping that his daughter's kidney is a match for him. However, in the screening process, testing revealed that his daughter is not genetically related to him. Neither Mr. P. nor his daughter know this. The transplant team consults the ethics committee, inquiring whether they should share this information with Mr. P. or his daughter. If so, should the wife be approached first?

COMMENTS FROM AN ETHICS CONSULTANT

I asked quite a number of my colleagues in healthcare concerning the question about what to tell the woman wanting to donate her kidney to her father who, it turns out, is not her biological father and that presumably neither she nor the father knew of this circumstance.* Almost to a person the reaction was to tell the daughter she was not a match and then just leave it at that. When I asked for a reason for this almost instinctual response, I generally heard something about privacy, stirring

up trouble, or perhaps that it was not relevant to the question of whether the daughter was an optimal donor. I would like to tease out a bit some rationale for making any decision about sharing the information about paternity. I have three questions.

First, who is the primary responsible agent? The answer seems to be the transplant clinician or whoever is the designated person who conveys the tissue matching results. Looking beyond that clinician, we might also say that the mother is also a moral agent who may be accountable for actions, but in the immediate situation, the agent who has primary responsibility is the one with special knowledge and very private information, and who may have the responsibility to take some action in a morally responsible way.

The second question is to whom is the primary moral agent responsible? Clearly, there is an important responsibility to the daughter who has submitted to a medical procedure in providing the blood sample for matching. Looking beyond the responsibility to the daughter, the clinician also has a responsibility to the father, who is a potential recipient of a kidney and who is suffering from chronic kidney disease. But it does seem that the primary responsibility is to the daughter who entrusted her blood sample to clinicians for matching with her father. Within the immediate medical sphere, the mother is not involved.

Finally we have to ask for what is the clinician responsible? It seems to many of the people I informally polled the answer to the "what?" question is to provide the medical response to the question, "Can I donate a kidney to my father? Am I a good match?" The most straightforward response is that of many of my colleagues: "On the basis of the lab test you are unable to donate a kidney to your father because you are not a good match." Of course the concern with this response is what if the daughter asks why she is not a good match? Also, is there some good medical reason for the response to be, "On the basis

of the test, it appears that you are not biologically related to your father"? There may be a good medical reason to offer more information, especially if the daughter needs to know if her father's chronic kidney disease is somehow genetically linked and, that not being the case, she need not worry about it and all the ramifications it may have for insurability or even securing a job. If there is a good medical reason to offer this important information, there probably is a good moral reason for sharing it.

We might also ask if there is some moral reason to share the information about paternity, whether there is a medical reason or not. Is there a moral reason to share the information based, perhaps, on the principle of reciprocity: "I would want to know, so, therefore, would others." I am not so sure myself, however, if I would want to know, and even if I did, does that mean other presumably rational persons would want to know too? If I were a clinician with a long term relationship with the daughter, I may have a better understanding of the daughter's values and desires and could answer the question of reciprocity. Of course in this case the daughter and the clinician more than likely are strangers to each other in a nonetheless potentially highly charged situation.

Probably the best approach, which is too late in this case, is to be proactive in obtaining informed consent for the procedure for obtaining the sample. It probably is important to tell people that non-paternity could be discovered by the test and then give them the option of whether they would want to know if that was one of the results. To have this option in the informed consent process makes very good sense, especially, as genetic counselor colleagues tell me, such results from testing are not uncommon.

Since in this case, the informed consent process did not include this option, we are still left with a conflict between the "right to know" and the principle of non-maleficence. It is easy to imagine,

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as my colleagues assert, that considerable harm could be caused by disclosure. Further, the mother, clearly an important person in this case, is not even a patient. Only the father and daughter are patients by going through the testing. The mother, however, could be harmed by the disclosure. Perhaps one could have a private conversation with her, letting her know of the findings and ask her how to proceed? She is the only one who presumably would not be surprised by the news. But that would entail providing private medical information (about the daughter) such that one would need her consent to share it.

I would tell the daughter that she was not a match and that there is no scientific and genetic link to her father's kidney disease. I would do that and then change the informed consent process, and I would not sleep well that night. That is what some folks call the moral remainder.

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**I want to thank the Center for Practical Bioethics discussion group for a discussion of this case. I particularly want to thank Terry Rosell, John Lantos, John Carney and our moderator Rosemary Flannigan for their insights.*

COMMENTS FROM A GENETIC COUNSELOR

The issue of the unintended discovery of non-paternity, described in the case study presented above, is a common ethical dilemma faced by genetic counselors. Interestingly, the case above poses the question of who the information should be shared with, father or daughter, and with what involvement of the mother. The wording of this question implies that the question is to whom the information should be disclosed, rather than whether

the information should be disclosed at all.

This question is particularly interesting because historically, genetic counselors, MD clinical geneticists and PhD medical geneticists believed that non-disclosure was preferable because it maintained the woman's confidentiality and did not disrupt the family unit (Pencarhina et al. 1992; Wertz & Fletcher 1988). It is difficult to determine with any level of certainty whether this is still the common belief, as most institutions now have policies which involve discussing the potential of identifying non-paternity during the informed consent process for any test that has the potential to reveal this information. Despite the ideal approach of preemptive discussion of all possible scenarios, incidental findings in clinical care and research are, to some extent, inevitable. Once faced with that scenario, what becomes paramount is how those results are handled. The best approach remains a matter for debate with a seemingly endless list of issues for consideration.

Prior to deciding whether or how to disclose, one must first consider the practical nature of the situation—whether it is possible to provide appropriate care without disclosing. That is, whether it is possible to disclose the results of the clinical test without disclosing the paternity issue. If it is not possible to do this, then non-paternity must be disclosed in order to provide standard care. In some cases it may be possible to present a clinical conclusion without revealing paternity, for example, a donor may be told “you are not a match” in a case where a 6/6 match is needed to proceed with a transplant but only a 3/6 match is expected for a biological child. In other cases this may not be possible. For example, if a 3/6 antigen match on HLA testing is an acceptable match for a donor and testing is done only to “confirm” what is presumably known, then the identification of non-paternity would alter the clinical course and would need to be revealed.

In the event that it is not possible, without compromising the clinical care of the patient, to avoid disclosure of

non-paternity, there remain many issues to consider: autonomy, nonmaleficence, deception, non-directiveness versus paternalism, risk, magnitude, privacy, truth telling and coercion. Of note, many of these considerations can be used both in the argument for and against disclosure.

When considering autonomy we must consider the autonomy of the patient awaiting transplant, the autonomy of the daughter who is being evaluated as a donor, and the wife/mother of the patient/donor. By disclosing the false paternity we would maximize the daughter's autonomy as well as the patient's autonomy. Disclosing this information would support the daughter's right to the information as an individual, potentially give her the opportunity to learn about her genetic heritage and biological paternal family history and would allow her to make an informed decision about organ donation in light of this new information. Further disclosure would support the patient's independent right to know that his daughter is not biologically his. Conversely, if we consider the autonomy of the wife/mother, we must respect her independent right to conceal this information.

The most common argument against disclosure is often that of nonmaleficence. Healthcare professionals are taught above all to do no harm and in situations of non-paternity it is difficult to determine with any level of certainty whether disclosure will be more or less harmful than non-disclosure. It would be unethical to ignore the possibility that disclosure could do irrevocable harm to the family, the extent of which may not be known, but the potential for psychological, physical, financial or other harms have all been considered and discussed throughout the literature.

Deception must be considered from both an ethical and practical perspective. First, is it *ethical* to actively deceive a patient and provide misinformation or limited information in order to hide an incidental finding such as non-paternity, and second, it is *practical* to do so? Consider the scenario wherein our transplant patient moves out of state. His

past medical records are requested by the medical center and the new treating physician (attempting to be empathetic) says, "I see from your chart notes that your daughter was going to donate a kidney to you but she was not a match, it must have been difficult to learn that she was not your biological daughter while going through the transplant process." With people moving from one area to the other or changing healthcare providers due to insurance constraints, medical records are actively shared as part of patient care on a regular basis. Once results have been documented in the medical record, it is very difficult to ensure that they are always kept confidential. In addition, release of the results in this accidental fashion means that the information is not likely to be disclosed in a sensitive manner with appropriate support.

In the midst of the considerations outlined above we must also consider who is the patient, and to whom is the obligation to provide care and protect privacy. At first thought, the individual awaiting transplant is the patient, however, once the daughter agreed to testing (in preparation of becoming an organ donor), she too became a patient of the transplant team. Since healthcare providers are morally obligated to protect the privacy of each patient, a new dilemma becomes apparent—there is no way to disclose non-paternity to either party without breaching the confidentiality of the other party.

I have not yet discussed risk, magnitude of risk, or coercion. There is, of course, a risk in any situation in which sensitive information is at stake, however, in cases of paternity it is important to consider previous interactions with the family to determine the magnitude of risk. If there was any suggestion of abuse in the past, this should be seriously considered in the determination of whether or not to disclose, as one can imagine abuse escalating in light of such information. Finally, there is the risk of coercion. Organ donors are more likely to be related to the recipient, and the likelihood of donating an organ

diminishes with the degree of relatedness, therefore, disclosing non-paternity may influence the daughter's interest in donating. Although difficult, the healthcare team must attempt to make a decision about disclosure that is independent from the transplant procedure to avoid withholding the information as a means of ensuring that the daughter will proceed with the transplant.

In the end, there is clearly no right or wrong answer. There are many ethical and moral considerations that could lead down either the path of disclosure or non-disclosure, so we are left with our best judgment, which may be different in every case of an incidental finding. In my opinion, once information has been identified and documented, it is very hard to maintain a secret, and certainly there is no guarantee that the secret will be kept by others in the future. As a result, I would argue for disclosure. Assuming that there is a well established relationship between the transplant team (including a psychologist) and the father, I would suggest disclosing to him first and then working with him to develop a plan (either with or without him, depending on his preferences) to disclose to the daughter. I would not involve the wife in the initial discussion, as she is not the patient, but I would encourage the transplant patient/father to consider speaking with his wife and having her involved in the disclosure to the daughter.

Erynn Gordon, MS, CGC
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Health Care Reform Cont. from page 5

efforts, playing out within the medical market place. All of our past reform efforts have aimed at achieving an ideal, but have typically fallen short. However, although we may never successfully land on the rocky coast of utopia, that does not mean we should not try.

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**I feel enormously fortunate that instead of dropping out of Medicare, I was given the opportunity to participate in a new financial model for providing care to frail elders living in a general community setting through Erickson Health Medical Group. This project brings high quality medical care to the Medicare population and does so through a mix of fee for service and managed care enrollees, in collaboration with nursing homes and assisted living facilities, whose residents benefit from the model. I am once again hopeful that this model will be able to deliver high quality geriatric medical care in a community setting in a manner that is sustainable, accountable and replicable.*

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JOINT COMMISSION ZEROES IN ON DISRUPTIVE BEHAVIOR

A new standard of the Joint Commission taking effect in January, 2009 will require hospital administrators to adopt codes that define disruptive staff behavior, and to develop procedures to discipline disruptive staff, including physicians. In July, the Commission issued a sentinel event alert describing the problem and recommending how hospitals should handle it. The alert defines disruptive behaviors as including “overt actions such as verbal outbursts and physical threats, as well as passive activities such as refusing to perform assigned tasks or quietly exhibiting uncooperative attitudes during routine activities.” Examples include “reluctance or refusal to answer questions, return phone calls or pages; condescending language or voice intonation; and impatience with questions.”

The commission recommends that hospitals educate staff about acceptable behavior, hold everyone accountable, and spell out how and when to begin disciplinary actions. Hospitals also should protect staff members who report bad behavior from retribution, and intervene early and in a constructive way with those accused of bad behavior.

The impetus for this new standard was informed by a survey about physician-nurse relationships. Rosenstein (2002) surveyed staff from 142 acute care, non-profit hospitals in the U.S.. Of the 2,563 respondents, over 90% reported witnessing disruptive physician behavior, the most frequent types being:

- Disrespect
- Berating colleagues
- Use of abusive language
- Condescending behaviors

Disruptive outbursts occurred most frequently in operating rooms, medical-surgical units, intensive care units, emergency departments, and obstetrics units. About two thirds of respondents

stated their hospitals had a code of conduct prohibiting disruptive behavior, but less than 50% thought their code was effective. Barriers to reporting disruptive behaviors were cited as one reason for this. Such barriers included:

- Fear of retaliation
- Belief that nothing ever changes
- Lack of confidentiality
- Lack of administrative support
- Physician lack of awareness or unwillingness to change.

Both physicians and nurses felt that it was only a few physicians who exhibited disruptive behavior, and both agreed that nurses were also guilty of exhibiting disruptive behaviors toward physicians. Of concern is that about 37% of respondents believed that nurses were leaving their workplace as a result of disruptive behavior. This is cause for concern given the current nursing shortage, and evidence that higher nurse-patient ratios and conducive working environments protect against such errors.

Some physician groups worry that the application of disruptive behavior policies will be too far-reaching, serving to silence physicians who speak out in the process of advocating for their patients. The American Medical Association recommends that policies distinguish between behaviors that represent good faith efforts to constructively criticize the workplace versus verbal or physical conduct that may negatively impact patient care. In addition, hospitals should verify allegations and discipline hospital staff fairly. For example, suspending a physician's hospital privileges should only be a mechanism of last resort.

Mechanisms that Rosenstein and colleagues (2002) identified to promote healthy interdisciplinary staff relationships include:

- Providing opportunities for interdisciplinary communication and collaboration;

- Offering education and training to physicians and nurses in team building, joint collaboration, conflict management, time management, stress management, and phone etiquette;
- Identifying a physician champion who can promote nurse-patient collegiality within the institution;
- Getting hospital administration's support to take disruptive behavior reports seriously;
- Handling reports of disruptive behavior confidentially, with prompt and fair follow-up.

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CALENDAR OF EVENTS

JANUARY

- 12 (5:30 pm - 7:30 pm) Ethics Grand Rounds: "Should Palliative Sedation to Unconsciousness be Limited to a Treatment of Last Resort?" New York Academy of Medicine's Ethics Grand Rounds. Speaker: Jeffrey Berger, M.D.. 1216 Fifth Avenue, New York, NY. For more information, visit <http://www.nyam.org/events/>.
- 26 (3:00 pm) "Mind Wars: Brain Research and National Defense," Speaker Jonathan Moreno, Ph.D.. Penn State, Foster Auditorium, 101 Pattee Library, University Park, PA. For more information, visit <http://www.psicc.psu.edu/news/calendar.asp>.

FEBRUARY

- 20-21 Ethics in the Intelligence Community. Sponsored by the International Intelligence Ethics Association, Johns Hopkins University at Mt. Washington, 5801 Smith Avenue, Baltimore, MD. For more information, visit <http://www.intelligence-ethics.org/>.

MARCH

- 2-5 4th Biennial Becoming an Ethics Consultant Conference. An Intensive 4-Day Training Course for Healthcare Professionals. Honolulu, Hawaii. Presented by the St. Francis International Center for Healthcare Ethics. For more information, call 547-6050, e-mail info@stfrancishawaii.org, or visit <http://www.stfrancishawaii.org/>.
- 6 2009 Ethics Conference in Raleigh, N.C.. Sponsored by the National Association of Social Workers. Visit <http://www.naswnc.org/> for more information.
- 9 (5:30 pm - 7:30 pm) "Transforming Health Care: Lessons from the West Coast for the East." New York Academy of Medicine's Ethics Grand Rounds. Speaker: Benjamin Chu, M.D., M.P.H. 1216 Fifth Avenue, New York, NY. For more information, visit <http://www.nyam.org/events/>.
- 31 (7:30 pm) "The Ethics of Aging," speaker Carol Hausman Ph.D., gerontologist and founding Coordinator of the Washington Jewish Healing Network. Sponsored by The Hebrew Home of Greater Washington. Jewish Community Center of Greater Washington, 6125 Montrose Rd., Rockville, MD.

RECONSIDERING MARYLAND LAW ...

How did the Maryland Patient Care Advisory Committee Act and the Maryland Health Care Decisions Act come to be? How do they influence health care ethics committees (HCECs) in Maryland? What goals were HCECs thought to achieve? Are they living up to those goals? Are HCEC members who conduct clinical ethics consultations improving the clinical climate at their institutions? Are they competent to do ethics consultations? What are "best practice" models for HCECs? Are there alternatives to an institutional HCEC? These and other questions were addressed at the December 3 conference, Health Care Ethics Committees and Maryland Law – Time for a Change?, sponsored by MHECN in partnership with Harbor Hospital and the Beacon Institute. To view speakers and the conference agenda, visit <http://www.law.umaryland.edu/mhecn>.

What did conference speakers and attendees propose as changes, if any, to Maryland legislation impacting HCECs? Stay tuned to the next issue of the Newsletter for a recap.

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